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Fostering Meaning Making in Grieving Adults with Intellectual and Developmental Disabilities

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Fostering meaning-making in grieving adults with intellectual and developmental disabilities

Teresa Graziano, Nursing

Introduction

People with intellectual and developmental disabilities (IDDs) cite problems with service delivery as a key restricting factor for adequate care. They report that health care providers (HCPs) and other staff have inadequate skills to meet their needs. There is a lack of literature regarding the best practices for HCPs, staff, and family when working with this population during times of loss. Without recommendations validated by research, HCPs, staff, and family run the risk of providing subpar support during a time of extreme vulnerability which results in isolation, disenfranchisement, complicated grieving, and unhealthy mourning.

This project targeted staff and family at a day program in Springfield, MA through an educational presentation and HCPs through an article with recommendations for care.

Methods

A thorough literature review was completed

- Parents and staff were given an educational presentation that focused on:
 - ❖ Interpersonal interaction
- ❖ Basic background in developmental models (Erikson's Psychosocial Stages)
 - ❖ Application to bereavement behavior
- ❖ Dual Model Process used for grief theory (Stroebe and Schut)
 - ❖ Personal experience

Those involved with bereaved families may turn to bereavement journals

- ❖ Write article outlining current recommendations for grieving individuals with IDD.

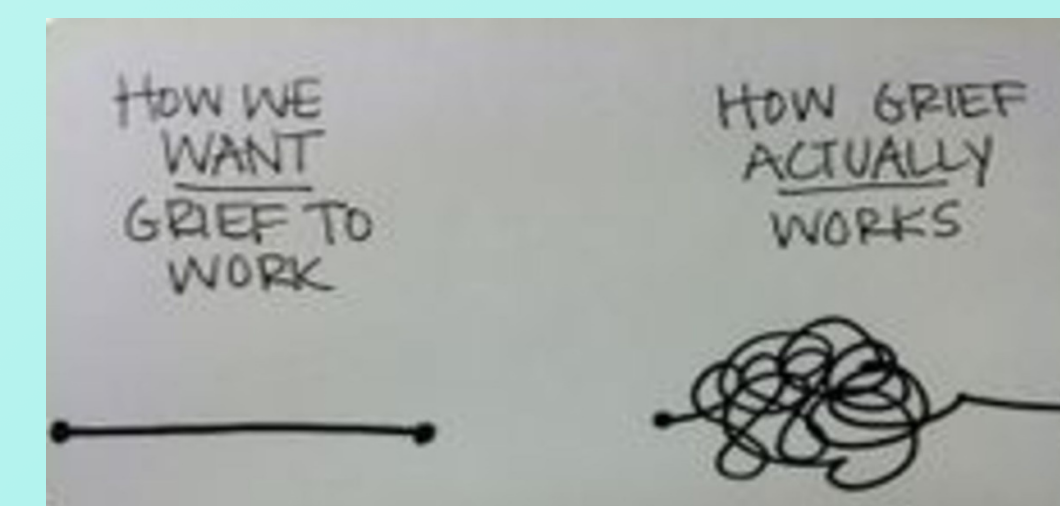
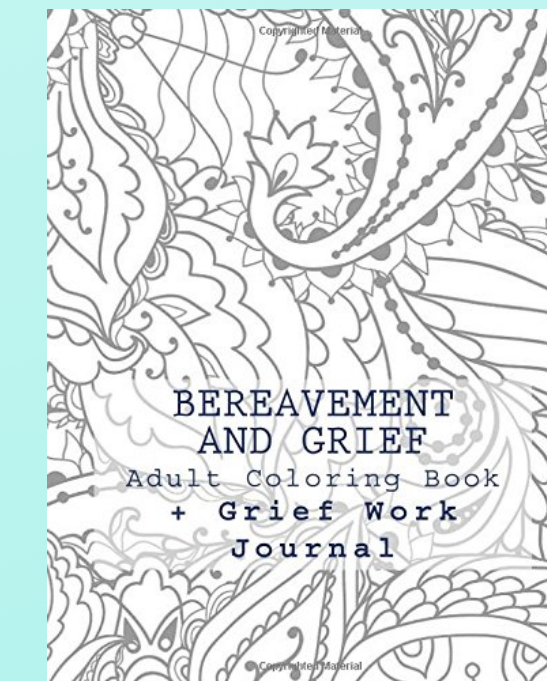
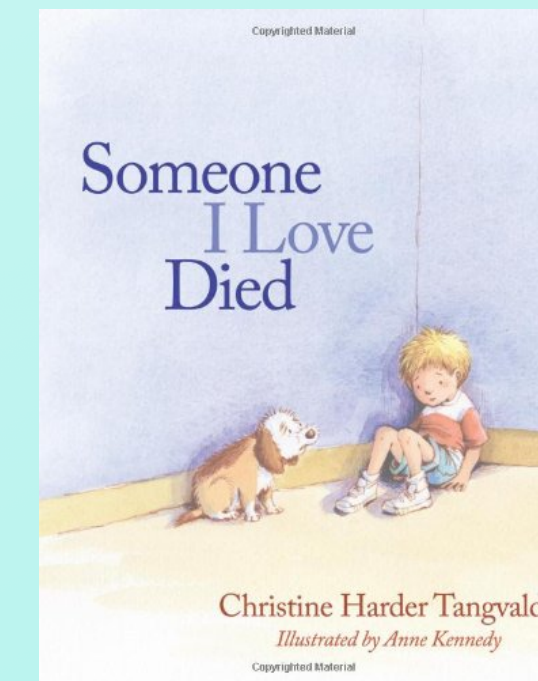
Results

When working with this group, the focus is on adjusting developmental expectations for their functional age rather than their chronological age. Each individual should receive individualized support.

Expression may be complicated by verbal ability, but *everyone* experiences and feels loss despite functional ability. Lack of emotional expression does not reflect absence of care towards their family and loss.

Therapeutic strategies that are beneficial:

- ❖ Music therapy
- ❖ Art therapy
- ❖ Drawing
- ❖ Prompted grief journals/coloring books
- ❖ Bibliotherapy (stories, books)
- ❖ Journaling, letter writing
- ❖ Give space when needed
- ❖ Ask “how can I help you”
- ❖ Allow participation in grief rituals



Discussion suggestions

- ❖ Be present, listen
- ❖ Give ample time for processing of questions as well as the formation and delivery of a response
- ❖ Use literal language, no euphemisms
- ❖ Use familiar communication devices, such as tablets or images
- ❖ Provide privacy and a calm environment with few distractions
- ❖ Pose opened-ended questions
- ❖ Consider what the family has told them
- ❖ Empower them to voice feelings; reassure that they will not be punished, and information will not be shared
- ❖ Reflect “why” questions back to the individual –what do they think?
- ❖ Don't stifle emotional expression based on expected age and gender norms

Touch may be therapeutic to some but may make others uncomfortable. Always ask permission before initiating touch.

Discussion

This population consistently receives care that is of lower quality than those without disabilities.

With validated and thorough support, individuals with IDD can expect feelings of empowerment; confidence to express thoughts, feelings, and wishes; increased development of knowledge and understanding; and assistance to make meaning of emotions and conflicts.

Furthermore, there is a need for the thanatology and medical community to assess current recommendations for bereavement care for those with IDD. Further research would improve outcomes for grieving individuals living with IDD.

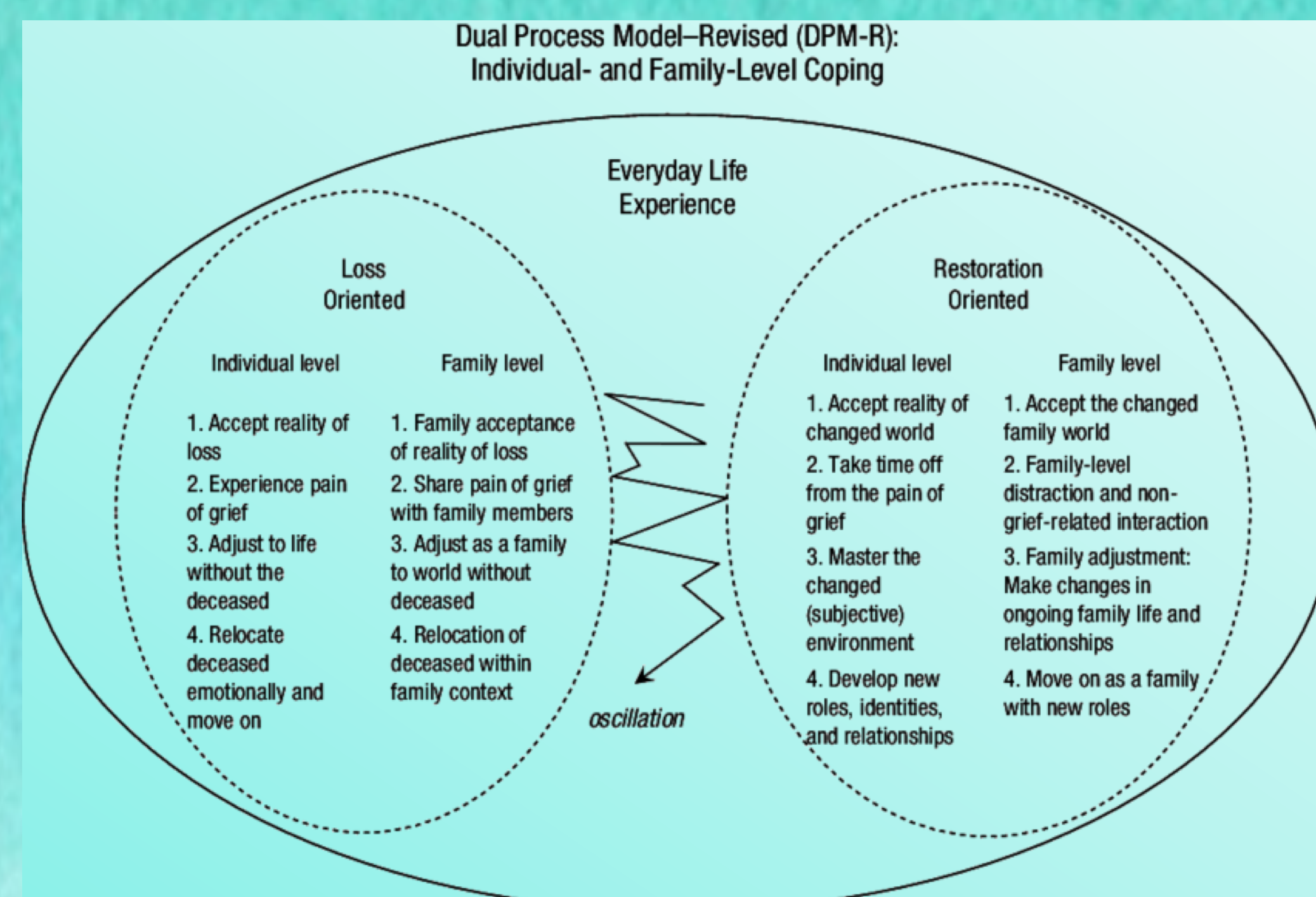
There is pain in this world that you can't be cheered out of. You don't need solutions. You need someone to see your grief, to acknowledge it. You need someone to hold your hands while you stand there in blinking horror, staring at the hole that was your life.

~ Megan Devine

in the new book, It's Okay That You're Not OK



#ItsOKYoureNotOK
refugeingrief.com/book



“Loss can be disempowering for anyone; but for people with an IDD loss can be totally *disempowering and overwhelming.*”

-Sue Read, *Supporting people with disabilities experience loss and bereavement*

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Acknowledgements

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